

STATE OF NEW JERSEY  
EXECUTIVE DEPARTMENT  
EXECUTIVE ORDER NO. 89

WHEREAS, New Jersey has one of the largest senior citizen populations in the nation; and

WHEREAS, currently, one in seven residents of this State is at least sixty-five years of age and, it is anticipated that, in thirty years, one in four New Jerseyans will be at least sixty-five years old; and

WHEREAS, these demographic projections indicate a critical need to anticipate and develop responses to the likely need of large numbers of elderly residents of this State for elder care and the needs of their care givers;

NOW, THEREFORE, I CHRISTINE TODD WHITMAN, Governor of the State of New Jersey, by virtue of the authority vested in me by the Constitution and by the Statutes of this State, do hereby **ORDER AND DIRECT**:

1. There is hereby established in the Department of Health and Senior Services the New Jersey Advisory Council on Elder Care.

2. The Council shall be composed of 17 members as follows:  
three members of the Senate to be appointed by the President of the Senate, no more than two of whom shall be members of the same political party; three members of the General Assembly, to be appointed by the Speaker of the General Assembly, no more than two of whom shall be members of the same political party; the Commissioner of the Department of Health and Senior Services, a Deputy Commissioner of the Department of Health and Senior Services, and the Director of Senior Services or their designees; and eight public members, all of whom shall be appointed by the Governor, who shall have an interest or expertise in issues pertaining to elder care.

3. It shall be the responsibility of the New Jersey Advisory Council on Elder Care to gather and evaluate information on the current and perceived future service needs of senior citizens and those caring for them, and to determine the current needs of independent elders and those anticipated during the next 25 years. The council shall, in particular, focus on the following issues: (1) the kinds of support or choices that care givers need now and will need in the future to help their patients, parents or loved ones maintain their dignity and independence; (2) the expectations that middle-aged persons currently have about the kind of care they will receive as senior citizens during the next 25-year period and how they

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expect to pay for that care; (3) the service delivery system that needs to be established or modified to meet anticipated elder care needs, and the kinds of legislative or policy decisions necessary for this purpose; and (4) the kinds of accommodations that need to be made for senior citizens who want to utilize various long-term care options.

4. The Council shall:

a. Organize as soon as practicable following the appointment of its members. The Governor shall appoint a chairperson from among its members. The council members shall serve without compensation.

b. The Council shall meet at the call of the chairperson at the times and in the places deemed appropriate and necessary to fulfill its charge. The council shall be entitled to call to its assistance and avail itself of the services of officials and employees of any State department, board, bureau, commission or agency as it may require and as may be available to it for its purposes.

5. The Council shall present a report of its findings and recommendations to the Governor and the Legislature no later than six months after the date of its initial meeting.

6. This Order shall take effect immediately.

GIVEN, under my hand and seal this  
28<sup>th</sup> day of September  
in the Year of Our Lord, One  
Thousand Nine Hundred and Ninety  
Eight, and of the Independence of  
the United States, the Two Hundred  
and Twenty-Third.

/s/ Christine Todd Whitman  
GOVERNOR

[seal]

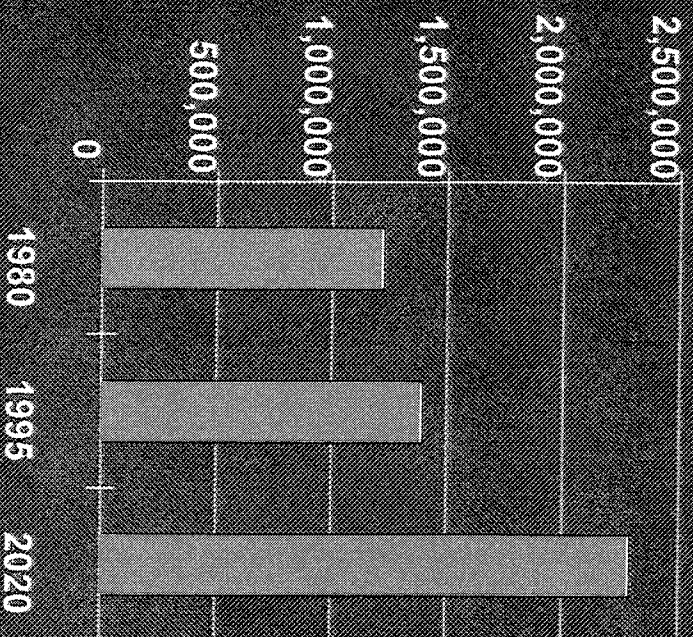
Attest:

/s/ John J. Farmer, Jr.

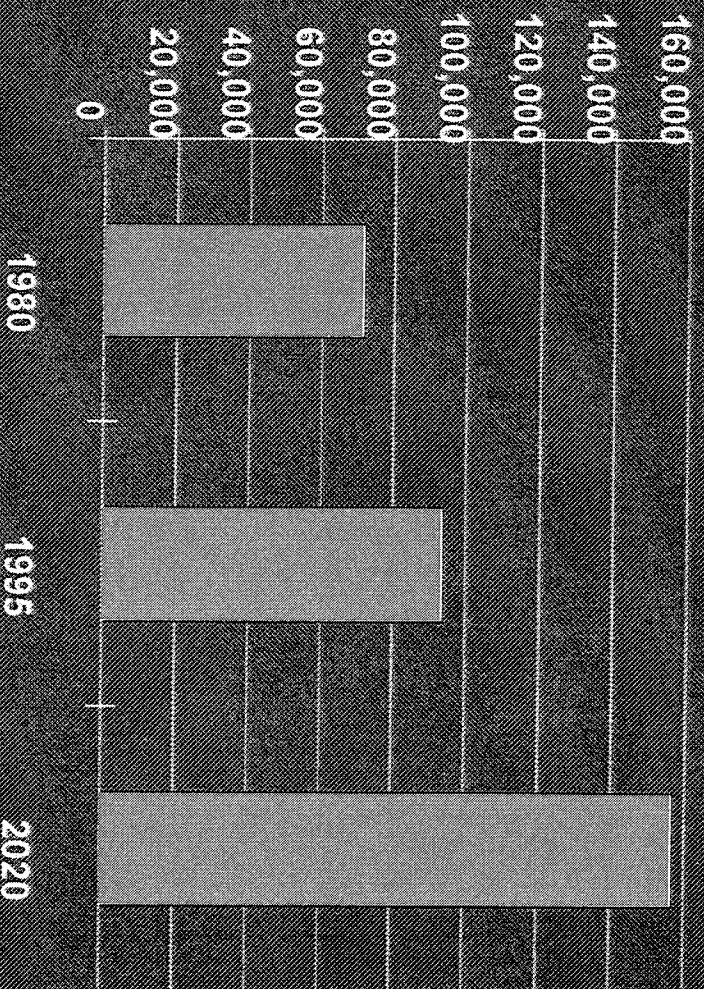
Chief Counsel to the Governor

# Growth in Senior Population

60+



85+





**NEW JERSEY**  
**ADVISORY COUNCIL ON ELDER CARE**

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ASSEMBLYWOMAN CAROL J. MURPHY, *Chair*  
101 GIBRALTAR DRIVE, SUITE 2D  
MORRIS PLAINS, NEW JERSEY 07950  
(973) 984-0922  
Fax: (973) 984-8094

Assemblywoman Carol J. Murphy,  
*Chair*  
Assemblyman Louis A. Romano  
Assemblyman Samuel D. Thompson  
Senator Wynona M. Lipman  
Senator Norman M. Robertson  
Senator Robert W. Singer  
Len Fishman, *Commissioner*  
Ruth M. Reader, *Ass't. Commissioner*  
Susan C. Reinhard, R.N., Ph.D.,  
*Deputy Commissioner*

Theresa L. Edelstein, M.P.H.  
Vivian E. Greenberg, A.C.S.W.  
John Michael Heath, M.D.  
Renee W. Michelsen, L.C.S.W.  
Roberto Mufiz, M.P.A.  
Joanne E. Patterson Robinson, Ph.D.  
Bernice B. Shepard  
Lennie-Marie P. Tolliver, Ph.D.

December 28, 1998

**INTERIM REPORT TO THE GOVERNOR**

In 1970, the United States Census showed that there were 679,000 people over the age of 65 living in the State of New Jersey. By 1990, that number had increased to 1,025,000 or an increase of 58%. During the same time period, the overall population of New Jersey had increased only 7.8%. According to the 1994 census update, New Jersey's total population is projected to grow from 7,930,996 to a total of 8,344,500 in the year 2005 and to 9,426,700 by the year 2030. Between 2010 and 2030, those persons age 65 years and older will increase by 68%, which is the impact of the aging of the "baby boomers."

Nationwide, nearly one in four households, or 22.4 million, are involved in caregiving for an elderly relative or friend. Caregiving is the provision of unpaid care to a relative or friend to assist the older person and allow him/her to remain in the least restrictive environment. It is typically performed by relatives and close friends for a person who is no longer able to manage all aspects of his or her daily life and/or personal care. By providing unpaid assistance and support to these older relatives and friends, caregivers may help to avoid or delay institutional placement of the older person.

The typical caregiver is a 46 year old, employed woman who also spends approximately 18 hours per week caring for her mother. Over 30% of caregivers are caring for two or more elderly relatives or friends. Sixty-four percent of caregivers in one national study by the National Alliance for Caregiving reported they were working full or part time. Half of them indicated having made some adjustment in their work schedule because of their caregiving responsibilities.

A second study, conducted by the National Family Caregivers Association, indicated that almost one out of four caregivers stated they had children under the age of 18 living at home. More than two out of every three respondents reported experiencing depression since becoming a caregiver. Only one-quarter of the respondents received help from other family members. Almost 75% of the caregivers anticipated that their caregiving responsibilities would exceed five additional years.

One of the experts presenting before the New Jersey Advisory Council on Elder Care was Peter Arno, a health economist with Albert Einstein College of Medicine, who estimated that there are between 712,000 and 836,000 caregivers in New Jersey. He indicated that the average care recipient receives informal caregiving services valued at approximately \$20,000 per year. Dr. Arno has conducted previous research surveys on caregiving and found that, on average, caregivers provided 17.9 hours of caregiving per week. He estimated the cost of informal caregiving in New Jersey to be approximately \$5.9 billion, using a rate of \$8.18 per hour. Dr. Arno concluded his presentation before the Advisory Council by recommending that "we should be seeking ways to support and strengthen informal caregivers rather than adding new and overwhelming responsibilities to the burdens they have already assumed."

By 2030, when the baby boomers reach age 65, approximately one in five Americans will be age 65 - almost 70 million, more than twice the number today. Societal changes will affect the supply of caregivers in the future:

- ◆ increasing divorce and remarriage rates;
- ◆ increasing geographic mobility;
- ◆ reduced birthrate and delayed childbearing;
- ◆ increasing number of women in the workplace.

*Comment: We must remember that we are speaking about and dealing with ourselves. This is not an issue of "them" - it is how we wish to care for current and future caregivers and their loved ones, which will become ourselves. We learned that the quality of life of the caregiver may have as much impact on the care the elder receives as does the "formal" health care system.*

1. The most consistent issue raised by caregivers was access to information and affordable services. Many caregivers were unsure how to access services they required. Older adults value their independence and their preference is to "age in place," where they can maintain control over their lives. The Department of Health & Senior Services has designed NJ EASE in an effort to create a consumer-focused system that facilitates access to services for older adults and their caregivers through uniform assessments, benefits counseling, care management, ongoing monitoring and reassessment. However, knowing the availability of services you require does not mean you can afford them. Many middle-class caregivers are unable to purchase the services they require to maintain their relatives at home without impoverishing their relative as well as themselves.

2. Care management is a consumer focused collaborative process which assesses the individual's needs, and plans, implements, coordinates, monitors and evaluates options and services to meet those needs. Many caregivers, due to stress and burden or their own physical, psychological or emotional limitations, are overwhelmed with the complexities of caregiving and the fragmented delivery system.
3. New Jersey needs to expand community support services for caregivers and their relatives. The vast majority of caregivers want to continue to care for their relatives at home. They requested expanded and affordable community services such as respite care, home health and day care services. Affordable housing alternatives, such as shared housing, assisted living facilities and programs, and alternate family care, need to be expanded, publicized and supported. Preventive health services for older adults need to be offered at the community level.
4. Education was a major issue raised by both caregivers and professionals. The caregiver needs to be recognized as a key member of the older adult's health care team. Likewise, professionals need to assume more responsibility in preparing and supporting the caregiver and assess his/her needs. Ongoing education about the elderly and their needs must be made available for: doctors, professionals, paraprofessionals, seniors and all residents as they prepare for their own aging process. There are multiple levels of education/training needs - information about accessing information access (e.g. "What is NJ EASE?") is one level. Another level of education need is caregiver training and preparation - how to cope once you learn about and are perhaps enrolled in various programs/systems. The role of supplemental care (or "case") management enters here, in both public and private systems, as does enhanced awareness about caregiver stress and supportive resources, hopefully *before* the caregiver's status adversely affects the elder. Also apparent was the need for another level of training directed toward specific issues - Alzheimer's care, for example - and targeted at specific audiences. Health care providers to the elderly have needs at all three levels, as do institutions and agencies.
5. The majority of caregivers fail to either identify themselves as caregivers or to recognize or address their own needs. When the role extends over a prolonged period without relief, they are apt to experience social isolation, extreme fatigue, anger, depression, thoughts of suicide and guilt. This result can have serious implications for both the caregiver and the care recipient, since research indicates that caregiver stress and burden can lead to elder abuse and/or neglect. Appropriate mental health services should be included in care management planning.
6. Many caregivers are forced to balance employment with caregiving needs. One recent survey reported that almost two out of three caregivers were employed (52 percent were employed full-time). Employers can assist caregivers by sensitizing managers, offering educational seminars, assisting with referrals for community services, and expanding benefits and work options, such as telecommuting.



Excerpts from testimony received at the public hearings:

**Testifier #1's** husband was diagnosed in 1979 with Alzheimer's disease and for 10 years he was cared for at home. As she described her situation, "My family joined together in the support of making it possible for my husband to be as independent as he could be for a very long time. Well, here we are, almost 20 years later." While at home, her husband attended adult day care. However, now he has been in a nursing home for almost 10 years. As a trained gerontologist, she had learned that most Alzheimer's patients live on for seven years. She explained, "We're skewing all the statistics. He's not very alert. He hasn't spoken in maybe five years. I think he knows when somebody comes to his bedside." She is concerned about her husband's "very limited quality of life," and stated, "It's really important that people know about Alzheimer's patients and about the stress that caregivers live under. When I put him into a nursing home, I really thought I'm not responsible any more. It doesn't work like that. You still have the responsibility, and you still care, and it's still stressful."

**Testifier #2**, a licensed practical nurse and certified massage therapist who takes care of her 97-year-old mother suffering from Alzheimer's disease at home explained, "In spite of my experience in caring for the ill, the elderly, the physically and mentally challenged, when it came time to take care of my mother, I didn't have the wherewithal. I have learned firsthand about serious depression. I remember as a nurse writing on my patients' charts about suicidal ideation. It's not somebody else's chart any more. If during the times when I really became depressed, I could have spoken to someone, that person would have been writing on my chart about suicidal ideation."

**Testifier #3**, at the age of 52, is in the process of relocating to New Jersey from Florida because his 82-year-old mother, who was taking care of his 102-year-old grandmother, developed Alzheimer's disease. This son, whose own life has been disrupted by the caregiving needs of his family, needs to start a new life and search for a new job in his home state of New Jersey. The home health aide respite services that his mother receives are, in his words, "a breath of fresh air." These services allow him the opportunity to take his mother to see her doctors to help with her own condition. He also surmises that without the respite program, both his mother and grandmother would today be Medicaid patients in a nursing home.

The testimony of **Testifier #4**, a caregiver for his 88-year-old mother, portrayed a mother and son who were "infected" with depression. However, once his mother was accepted into the Statewide Respite program, she began to enjoy companionship and care. She began to attend an adult day care center, and as her son described, his mother's outlook improved. "Suddenly my mother was going to meet new people. It renewed her interest in her appearance. A trip to the beauty parlor, some new clothes and her spirits became lighter. She now had something to look forward to each week."

**Testifier #5**, testifying on behalf of the Morris County Senior Service Providers Group, and

**Testifier #6**, Executive Director of the South Jersey Chapter of the Alzheimer's Association, reaffirmed the importance of respite care for caregivers. They also expressed the need to increase affordable care for those who do not qualify for the Statewide Respite program. Joann explained that the continuum of respite services is available if a person is financially able or if a person meets eligibility requirements. However, she stated, "It is those in the middle that often have the fewest options available." Both supported the use of a sliding scale of fees to increase accessible, affordable options.

**Testifier #7** testified that she was a caregiver for her mother who was also a caregiver to her maternal grandmother. Both elderly women had cancer. What is particularly interesting about this three-generational caregiving scheme is that she did not realize that she was a caregiver until almost the end of her four years as one. She works with the Department of Human Services and through her job knew Nancy Day at the Department of Health and Senior Services. In Caroline's own words, "Only after I had gone through the majority of this . . . and after talking to Nancy did I realize that I was a caregiver. Without Nancy's help, I don't think I would have made it through this. Every time I had a problem, I could call Nancy, and Nancy would put me in contact with various people to help me care for my mother. But I believe that a lot of people don't realize that they're caregivers when they are. I never realized it in four years . . . More people need to realize and need assistance in realizing that they are caregivers, and they really need the support."

**Testifier #8**, whose wife was diagnosed in 1989 with Alzheimer's disease, was her caregiver for seven years before she had to enter a nursing home. One of his greatest concerns "was to learn what a caregiver is and how to become an effective one of long duration. If I could have had information from a single source in a non-fragmented manner to alert me of what my future would be like as a caregiver, it would have been of considerable help." (NJ EASE)

**Testifier #9**, Director of the Families and Health Care Project at the United Hospital Fund in New York City, presented highlights from a report from the United Hospital Fund called "Rough Crossings: Family Caregivers' Odysseys through the Health Care System," which focuses on the types of problems caregivers face -- lack of preparation and anxiety about the proper way to care for their loved one and the isolation that accompanies long-term caregiving. Regardless of her experience in the health care profession, she found that "nothing in my professional background, or my experience as a mother of three children, had prepared me to be the caregiver for a severely disabled, brain-injured husband." As she described her situation, "I had to fight through layers of bureaucracy for ten days to get a dangerously unstable hospital bed replaced at home. Then when the bed arrived -- without notice, in the evening when there was no one to help me move him -- it turned out to be the wrong bed." She explained that she is "one of the more than 25 million . . . family caregivers who are struggling with the fragmented, inflexible and increasingly complicated collection of institutions and agencies called 'the health care system.'"

**Testifier # 10**, Corporate Director of Senior Health Services for the Saint Barnabas Health Care System, expressed a "real need for practical training of caregivers who provide physical care to a

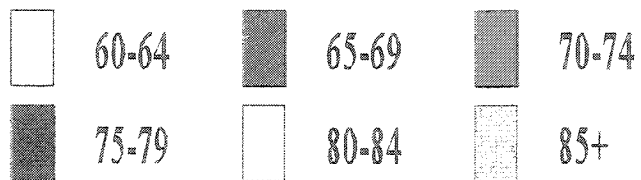
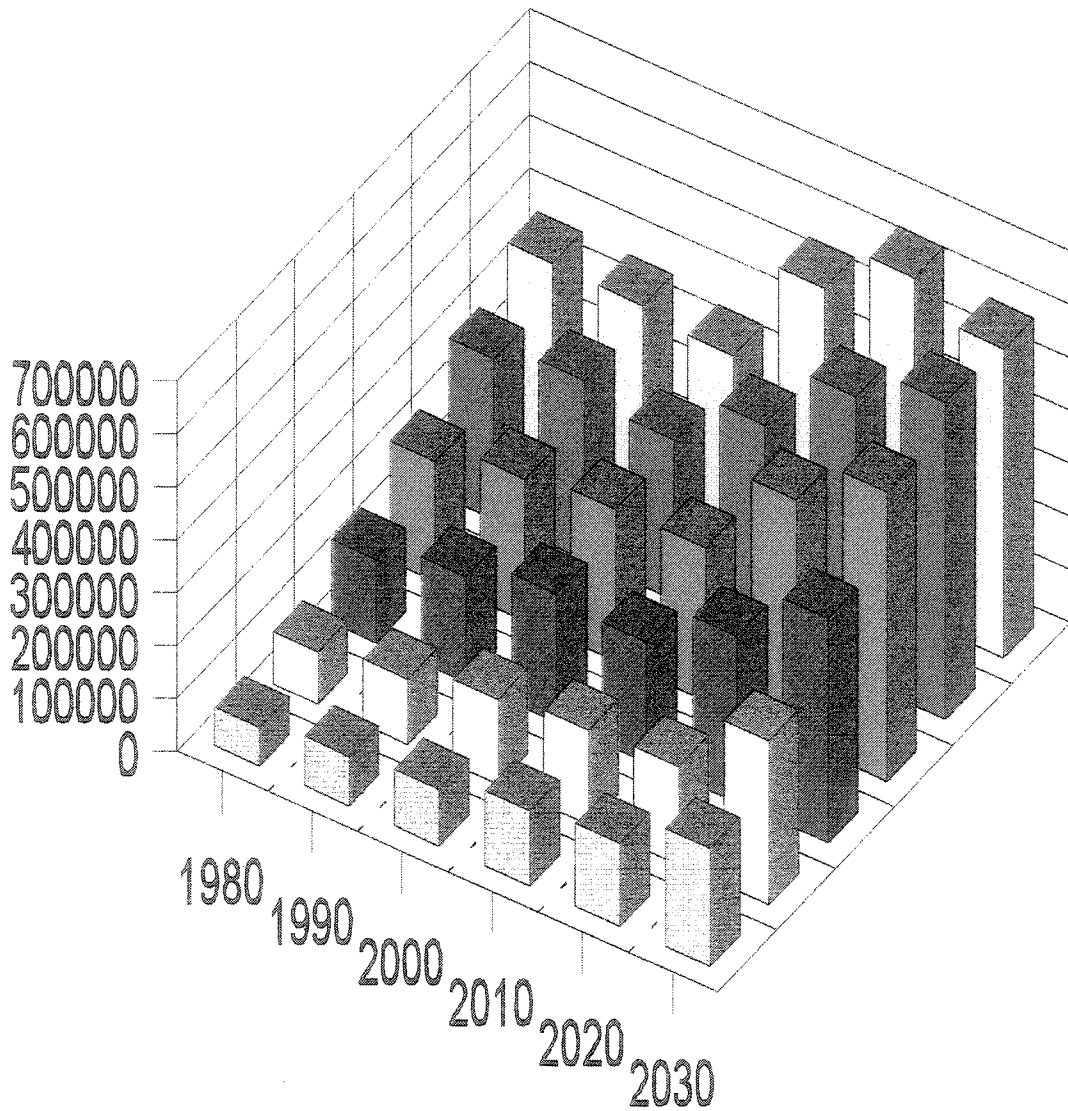


loved one in the home. Most of our hands-on caregivers have no training or support on how to adapt the home environment to a chronically ill, high-risk family member. Making the home Alzheimer's proof . . . using good body mechanics to lift and transfer a loved one, where are these caregivers to learn such skills? For the most part, they have no where to turn. Instructions given to a caregiver in the hospital prior to discharge are frequently information that is not quickly or thoroughly absorbed. Anxiety is high, staff may be rushed, and the principles of learning are difficult to achieve. I'm suggesting two types of caregiver education, both informational and practical hands-on experience. My recommendation must be a provision also for respite care, which will enable caregivers to attend such events addressing education and support. We have offered excellent caregiver presentations within the Senior Health Network at Saint Barnabas. However, if the caregiver can't leave their loved one to attend when that happens, we are all defeated. In certain instances, we have been able to provide free adult day care through our centers for caregivers to utilize when they attend educational sessions. If, however, the family member is bedridden, we cannot always intervene. Therefore, my recommendation on caregiver education must include a vehicle or provision for respite care."

**Testifier #11**, who is a geriatrician and an Associate Professor of Clinical Medicine at the University of Medicine and Dentistry of New Jersey - School of Osteopathic Medicine, where she serves as Director of the Center of Aging, stated that she sees "families and caregivers under stress due to the daily challenges of providing care for someone at home . . . choices people are forced to make - a choice between buying food or purchasing needed medication; a choice between remaining at home or placement in an institution because there is no one to help." She advised, "As a geriatrician, I see the all-important link between the medical, psychosocial and community-based interventions needed to preserve the older individual's function and independence. I know that care management is the key to negotiating the system and instituting early intervention measures to prevent complications and contain costs."

**Testifier #12**, a licensed clinical social worker who is also a long-term care consultant, raised questions about end-of-life decisions. Speaking on behalf of the increasing number of seniors who are over the age of 85 she explained, "Long life with health is everyone's dream. Dying without suffering is everyone's hope . . . We strive for a quality to our living and our lives; we hope for and need to assure a quality in our dying . . . We have reached a level of medical and technological sophistication that has enabled physicians to extend and prolong life. . . The problem of becoming dependent on sustained medical intervention becomes a reality." She expressed her "belief that most individuals with capacity for decision making would not choose to be kept alive in this last stage of life . . . if it did not enhance the quality of their lives and merely prolonged the dying process."

# Projected Growth of 60+ in NJ



1998-1999 New Jersey State Strategic Plan on Aging